

# IMMUNIZATION REGISTRY FOCUS GROUP STUDY

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Bilingual Hispanic Higher education

Miami, Florida

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## SECTION 1: GENERAL IMMUNIZATIONS AND HEALTHCARE

### I. Prevention

Diseases mentioned:

- Polio
- Cancer
- AIDS
- Tuberculosis
- Hepatitis

### II. Immunization

#### A. *Reasons not to get vaccinated*

- Religion
- Reliance on faith healing
- Lack of financial resources

#### B. *Reasons to get vaccinated*

- To avoid getting ill

#### C. *Ways parents are reminded of vaccine schedule*

- Personal record card given at birth of child
- Reminders from doctors, clinics and schools
- Reminders on television

Respondents said that publicity about immunizations in shopping centers and other public places would help them remember about immunizations.

## **SECTION 2: IMMUNIZATION REGISTRIES**

### **I. Initial reactions to the idea of a registry**

#### ***Positive reactions:***

- Useful when records are lost or misplaced
- Will save time and money in circumstances when an additional trip to get records from a doctor might be necessary
- Will prevent being immunized twice for the same thing
- Will provide information about negative reactions and side effects

#### ***Negative reactions/concerns:***

- Accuracy and confidentiality of the information

#### ***Other concerns:***

- Who will control the registry?
- Will there be any cost to the individual or taxpayer?
- How current will information be? Who will be responsible for updating information?
- How difficult will it be to correct errors?
- How universal will the participation in the registry be?

### **II. Content of the registries**

#### ***A. Initial reactions to the type of information typically in a registry***

- All respondents were positive about the inclusion of:
- Vaccine's expiration date
- Who administered the vaccine
- Notations about any adverse reactions
- Name of the child's father

#### ***B. Reactions to including home address and phone number***

- Only a minority of respondents felt this information was important. They said it would assist with communications.
- Most respondents felt this information should not be included due to frequent relocations and confidentiality. They said that their doctors had this information, if it was needed.

#### ***C. Reactions to including parent or child Social Security number***

- Most respondents said it was important to include the child's SSN to avoid any confusion between children with similar names.
- Many respondents felt the inclusion of the parents' SSN was intrusive.

***D. Reactions to including healthcare members enrollment (WIC, Medicaid numbers)***

- Because these agencies already have their information, respondents did not object to the inclusion of these numbers.

### **III. Access**

***A. Who should have access***

- Doctors
- Pharmacists
- Emergency room personnel
- Day care and school administrators
- Parents
- Insurance companies
- Medical researchers

***B. Who should not have access***

- Businesses
- Extended family members
- The public

Respondents felt that linking the registry with other health systems would be a good idea as long as there are safeguards that prohibit non-essential inquiries.

### **IV. Consent and Inclusion**

***A. Reactions to “opting out” option***

- Most respondents said this option was beneficial and efficient. They liked its ability to include children whose parents tend to be neglectful or too busy to take action. This option would also include children whose parents did not understand information about the registry.
- A few respondents disliked this option. They felt it was too passive and assumed that parents would want their children registered.

**B. Reactions to “consent” option**

- This was the most popular option. Respondents liked having the decision to register in the hands of parents. They preferred to be active and in charge of their children’s lives.
- Respondents agreed, however, that this option would be a disadvantage for children whose parents are neglectful and/or forgetful.

**C. Reactions to “automatic” option**

- While they thought this option would be beneficial for children, respondent disliked this option. They were opposed to having no choice.

**SECTION 3: WRAP UP AND CLOSING**

**I. Most important benefit(s) of registries**

- Fast, easy access to their children’s records
- Preventing duplication of immunizations
- Assistance to doctors and parents in following up on immunizations
- Quick replacement of lost information
- Warnings about adverse reactions to some vaccinations

**II. Greatest concern(s)/biggest risk(s)**

- Breaches of confidentiality
- Denial of medical benefits to those who may choose not to participate in the registry

**III. Influence of healthcare provider in decision to participate in a registry**

- Most respondents said they would consider their doctors’ recommendations about the registry but indicated that they themselves would make the final decisions.

**IV. Suggestions/comments to people who are responsible for how system works**

*The registry should be as universal as possible for the benefit of all kids around the world.*

*It will be very important to make sure that everything is extremely accurate. Mistakes could make a big difference in a child’s life.*

*Make sure that not everybody can get access to the system. They should have passwords.*

*Who will enter the information and who will have access?*

*Will I have any control over my child’s records? Will my pediatrician play any role?*

*Please be accurate. Specify the child's allergies. Let me know when the next vaccinations are due.*

*I would like for this to be extremely accurate and secure.*